Treatment Decisions About Defective Newborns: An Analysis of Current Attitudes

An Honors Thesis (ID 499)

by

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INTRODUCTION

The moral and ethical problems surrounding decisions about treatment of severely deformed newborns have received much attention in the medical literature of recent years. A wide range of attitudes is exhibited in contemporary literature, as evidenced in fourty-four articles written by doctors, ethicists, and laymen which have appeared in professional journals between 1973 and the present. Many of the articles appear somewhat artificially objective, overremoved from the environment in which the decisions must be made on a daily basis. Regardless of the possible desirability of this remote, dispassionate analysis, it may be questioned whether the attitudes of practicing neonatologists, who are constantly and deeply involved in such decision-making, are accurately reflected in the current literature. A comparative examination of attitudes toward treatment or nontreatment of defective newborns and about the decision-making processes involved, as revealed in the literature and as expressed by neonatologists in personal interviews, may aid in an assessment of the validity and/or feasibility of the various courses of action advocated in the current literature.

LITERATURE REVIEW

Many different definitions of severely defective newborns can be found in the literature. Criteria vary from

extremely low birth weight (Schechner, 1980; Fitzhardinge, 1976; Avery, 1975) to severe spina bifida (Heymann, 1975), chromosome disorders (Anon., Lancet, 1979a), and other congenital anomalies, including but not limited to brain damage (Black, 1979; Jonsen, 1975). Views on the ethics of treatment versus non-treatment of these infants are even more diverse. The most common position seems to be that nearly all babies should be treated, but a few of the most severely deformed should be allowed to die (Lipson, 1981; Jonsen, 1978; Pauli, 1978). Few of the writers, however, agree about the criteria which should be used in the decision-making process or the persons who should make the decisions. The arguments in favor of maximal treatment of all newborns are based variously on current civil and criminal law (Cooperman, 1977; Darling, 1977; Gustafson, 1973), the uncertainty of early diagnosis (Anon., Journal of Medical Ethics, 1981; Sherlock, 1979; Jonsen 1975), and/or the sanctity of all human life (Dundon, 1980; Jones, 1980; Lejeune, 1980; Sanders, 1979).

The question of the proper person or persons to make the decision about treatment of defective newborns is heatedly debated in the literature. The most prevalent stance is that parents with physicians should choose whether or not to treat, with the parents in most cases having the final say (Anon., Lancet, 1980; Revill, 1979; Fletcher, 1975). On the other hand, many writers maintain that parents are the worst people to make the decision, due to emotional strain and/or

conflicts of interest (Fost, 1981b; Cassell, 1978; Steinfels, 1978). Some would give doctors the power to decide (Fost, 1981a; Reid, 1977; Anon., Lancet, 1975), while others say that physicians are unqualified to make ethical decisions and may, like parents, have a conflict of interests (Stinson, 1981; Henry, 1980; Waldman, 1976). Society, in the form of hospital ethics committees (Haller, 1978; Stevens, 1976; Heymann, 1975) or court decisions and government commissions (Steinfels, 1978; Duff, 1976; Heymann, 1975), is called upon at times either to make the decision or to cast the deciding vote. The great need for education of and communication between parents and physicians is pointed out by many writers (Robertson, 1981; Anon., Canadian Medical Association Journal, 1980; Berseth, 1980).

Several sets of criteria have been proposed for use in treatment decisions about neonates. Of these, Lorber's is the most widely known and the most controversial (Black, 1979; Reid, 1977; Veatch, 1977). He uses the following medical criteria for deciding whether or not to treat children with myelomeningocele: the site of the spina bifida, paralysis, gross distortion of the spine as a result of, for example, kyphosis, gross hydrocephalus, and other gross congenital malformations. Some authors mention other criteria, including various enumerated congenital anomalies (Robertson, 1981; Campbell, 1979a; Veatch, 1977), extremely low birth weight (Schechner, 1980; Fitzhardinge, 1976), and loss of

function of part or all of the brain (Black, 1979; Campbell, 1979a, Anon., Lancet, 1975). Down's syndrome, mild to moderate spina bifida, and moderate prematurity are not generally considered valid criteria for non-treatment (Robertson, 1981; Smith, 1981; Campbell, 1979a). Some writers hold that only extremely severe cases should go untreated (Robertson, 1981; Black, 1979; Waldman, 1976), while others argue that no rigid criteria can be set and that each case must be judged individually (Campbell, 1979a; Veatch, 1977). Many point out that decisions should be made with an eye to the best interests of the infant (Robertson, 1981; Heymann, 1975; Jonsen, 1975).

It is often emphasized that there are nonmedical factors which have a bearing on treatment decisions (Black, 1979; Campbell, 1979a; Heymann, 1975). The quality of life of the child is often mentioned, including freedom from suffering (Coburn, 1980; Anon., Lancet, 1979a; Jonsen, 1975). The fate of untreated patients is also a concern (Black, 1979). The effect on the family is frequently discussed; some writers point out the possible benefits, or at least lack of hardship, to the family (Sherlock, 1979; Darling, 1977; Stevens. 1976), while others are concerned about the negative effects on the child's parents and siblings (Fost, 1981a; Campbell, 1979b; Heymann, 1975). The questionable legality of nontreatment decisions is often mentioned (Anon, Lancet, 1979b; Sherlock, 1979; Waldman, 1976). Other factors include

the moral effects of the practice of euthanasia (Black, 1979) and the financial costs of treatment to society (Heymann, 1975).

One of the common themes in the literature is the importance of acting in the best interests of the neonate (Stinson, 1981; Fletcher, 1975; McCormick, 1974). The interests of the child are usually, although not invariably, placed before the interests of the family (Fost, 1981a; Pauli, 1978; Gustafson, 1973). The huge financial costs to society are sometimes mentioned (Henry, 1980; Cooperman, 1977; Jonsen, 1975), but the responsibility of society to care for its members is emphasized as well (Coburn, 1980; Heymann, 1975).

General information about research methods, including content analysis, index construction, interviewing techniques, and tabulation of data was obtained from a textbook on social research (Babbie, 1975). A somewhat more extensive discussion of the assessment and quantification of attitudes was also consulted (Girod, 1973).

MATERIALS AND METHODS

The following set of six questions was developed and used to determine attitudes both in the literature analysis and in personal interviews with neonatologists.

1. How would you define a severely defective newborn?
2. Do you make an all-out effort to save the life of every live-born infant, even those that fit your definition of severely defective?

3. Who do you feel should be involved in the process of deciding whether or not to treat an infant, when there is time to make the decision?

4. What criteria do you use to decide whether an infant should be treated?

5. What factors other than the physical condition of the infant may influence your decision?

6. In making the decision of whether or not to treat, whose interests are the most important: the neonate's, the family's or society's? If you see a strong conflict among these, whose interest should take precedence?

Method of Literature Analysis

Fourty-four journal articles were identified by making an online computer search of the Medline files (files 152, 153 and 154; 1966-1982) of Dialog and by consulting the bibliography following "INFANTS: Public Policy and Procedural Questions" in The Encyclopedia of Bioethics (Reich, 1978). Photocopies of all applicable articles were obtained. The earliest article used was published in 1973; the most recent ones were published in 1981.

In each article, quotations which applied to any of the six questions listed above were underlined with felt-tip markers, using a color code for easy identification. Two hundred and eighty-seven quotations were marked. The quotations were then copied onto 3"x5" index cards, one quotation per card, color coded as before. The cards were sorted by

the questions which they addressed. Results were tabulated for each question, both by the number of quotations demonstrating a particular attitude and by the mumber of articles from which the quotations were drawn. The categories for the tables were determined by initial qualitative examination of the results. A certain amount of subjectivity was unavoidable in the categorization of quotations, but an attempt was made to remain as close as possible to the original intent of the articles by making the quotations of sufficient length to indicate their context and by referring back to the original article if there were doubt about the meaning of a statement.

After tabulation of the raw data, percentages were computed. Within each table, the percentages of quotations for each response were found. Following each table, the percentages of the total 287 quotations and 44 articles which addressed the question of that table were recorded.

Results of the literature analysis were compared qualitatively with the results of the personal interviews in the discussion.

Personal Interviews

Three neonatologists at three different Indiana hospitals were interviewed. The questions used were the same six that were applied to the literature. Identical report sheets were used for each interview to ensure anonymity of the doctors. The doctors were contacted by letters in which they

were told about the project and invited to participate in it. A stamped addressed postcard was included with each letter; the doctors were asked to sign an informed consent statement on the postcard and to include a telephone number through which the interview could be arranged, if they were willing to help with the project. (See Appendix for letter, response card, and report sheets.) Each interview took no more than thirty to fourty minutes.

The interview response sheets were treated in the same way as the articles. Relevant comments were underlined and transferred to note cards. Results were tabulated using the same categories as were used for the literature, where applicable. Percentages were calculated for the quotations, as in the literature analysis. No counterpart of the "number of articles" column was needed, since all doctors answered all questions.

Table 1: How would you define a severely defective newborn?

Response in the literature	No. of quotes	% of total * no. of quotes	No. of articles
Low birth weight	7	58.4	4
Multiple congenital anomalies	2	16.7	2
High lesion spina bifida	1	8.3	1
Severe brain damage	1	8.3	1
Severe chromosome disorders	1	8.3	1

*Percent of the total number of quotes referring to this question which gave this response

In addition, 6 articles dealt specifically with myelomeningocele and 1 dealt with Down's syndrome.

% quotes which referred to this question of total number of quotes = 4.2%

% articles which referred to this question, including the seven which dealt with specific topics = 36.4%

Response of neonatologists	No. of quotes	% of total no. of quotes
Long-term severe functional limitations	2	66.7
Multiple congenital anomalies	1	33.3

Table 2: Do you make an all-out effort to save the life of every live-born infant, even those that fit your definition of severely defective?

Response in the literature	No. of quotes	% of total no. of quotes	No. of articles
Withhold treatment under certain conditions	46	68.7	21
a) Conditions unspecified	29	43.3	15
b) Child may live -questionable quality of life	12	17.9	7
c) Child would die even with treatment	5	7.5	4
All-out effort in every case	21	31.3	12

% quotes which referred to this question of total number of quotes = 23.3%

% articles which referred to this question of total number of articles = 75%

Response of neonatologists	No. of quotes	% of total no. of quotes
Withhold treatment if child would die even with treatment	5	55.6
Withhold treatment if quality of life very questionable	1	11.1
Make all-out effort at first	3	33.3

Table 3: Who do you feel should be involved in the process of deciding whether or not to treat an infant, when there is time to make the decision?

Response in the literature	No. of quotes	% of total no. of quotes	No. of articles
Parents with physician make decision	35	49.3	22
Medical staff makes decision	25	35.2	15
Third party makes decision: hospital/community committee, gov't commission	11	15.5	6

% quotes which referred to this question of total number of quotes = 24.7%

% articles which referred to this question of total number of articles = 97.7%

Response in the literature*	No. of quotes	% of total no. of quotes	No. of articles
Doctors alone should <u>not</u> make decision	8	61.5	6
Third party should <u>not</u> make decision	5	38.5	4

*These quotations were all different from those used above.

% quotes which referred to this question of total number of quotes = 4.5%

% articles which referred to this question of total number of articles = 22.7%

Table 3: continued

Response in the literature	No. of quotes	No. of articles
Courts of law should make decision if involved parties can't agree	4	3

% quotes which referred to this question of total number of quotes = 1.4%

% articles which referred to this question of total number of articles = 6.8%

Response in the literature	No. of quotes	No. of articles
Better education of and communication between families and doctors is needed	4	3

% quotes which referred to this question of total number of quotes = 1.4%

% articles which referred to this question of total number of articles = 6.8%

Response in the literature	No. of quotes	No. of articles
Shouldn't make hasty decisions: provide initial care, then make decision	2	2

% quotes which referred to this question of total number of quotes = 0.70%

% articles which referred to this question of total number of articles = 4.5

Table 3: continued

Response of neonatologists	No. of quotes	% of total no. of quotes
Parents with physician make decision	6	66.7
Medical staff makes decision	3	33.3

Response of neonatologists	No. of quotes
Parents not only decision-makers --will go against their wishes for baby's good	5
Better education of and communication between families and doctors is needed	4
Shouldn't make hasty decisions: provide initial care, then make decision	3

Table 4: What criteria do you use to decide whether an infant should be treated?

Response in the literature	No. of quotes	% of total no. of quotes	No. of articles
Lorber's criteria*	5	20.0	4
Severe brain malformation	4	16.0	3
Treat virtually all infants	4	16.0	3
Life not in child's best interests**	3	12.0	2
Down's is <u>not</u> criterion for non-treatment	3	12.0	3
No rigid criteria can/should be established	3	12.0	3
Low birth weight	2	8.0	2
Little or no potential for intelligence	1	4.0	1

*Lorber's criteria: site of the spina bifida, paralysis, gross distortion of the spine as a result of, for example, kyphosis, gross hydrocephalus, and other gross congenital malformations (Reid, 1977)

**This includes inability to survive infancy/life of extreme pain

% quotes which referred to this question of total number of quotes = 8.7%

% articles which referred to this question of total number of articles = 7.3%

Table 4: continued

Response of neonatologists	No. of quotes	% of total no. of quotes
Anomalies incompatible with life	3	37.5
Extremely low birth weight	2	25.0
Trisomy 13, 18	1	12.5
Profound irreversible asphyxia	1	12.5
No rigid criteria can/should be established	1	12.5

Table 5: What factors other than the physical condition of the infant may influence your decision?

Response in the literature	No. of quotes	% of total no. of quotes	No. of articles
Emotional and financial costs to the family should be considered	12	66.7	9
Emotional and financial costs to the family are not relevant or not severe	6	33.3	3

% quotes which referred to this question of total number of quotes = 6.3%

% articles which referred to this question of total number of articles = 27.3%

Response in the literature	No. of quotes	No. of articles
Non-treatment is/may be illegal	14	9

% quotes which referred to this question of total number of quotes = 4.9%

% articles which referred to this question of total number of articles = 20.5%

Response in the literature	No. of quotes	% of total no. of quotes	No. of articles
Quality of life of the child is a legitimate factor	5	71.4	5
Quality of life of the child is not a legitimate factor	2	28.6	2

Table 5: continued

% quotes which referred to above question of total number of quotes = 2.4%

% articles which referred to above question of total number of articles = 15.9%

Response in the literature	No. of quotes	No. of articles
There are other (unspecified) factors to be considered	6	5

% quotes which referred to this question of total number of quotes = 2.1%

% articles which referred to this question of total number of articles = 11.4%

Response in the literature	No. of quotes	No. of articles
Cost of non-treatment is great, since the child may live	2	1

% quotes which referred to this question of total number of quotes = 0.7%

% articles which referred to this question of total number of articles = 2.3%

Response in the literature	No. of quotes	No. of articles
Should treat if parents want child, even if poor prognosis	1	1
Should treat child even if parents don't want it	1	1

Table 5: continued

% quotes which referred to above question of total number of quotes = 0.7%

% articles which referred to above question of total number of articles = 4.5%

Response in the literature	No. of quotes	No. of articles
Adverse moral effects of practising euthanasia	1	1

% quotes which referred to this question of total number of quotes = 0.4%

% articles which referred to this question of total number of articles = 2.3%

Response in the literature	No. of quotes	No. of articles
High cost to society of treating defective babies	1	1

% quotes which referred to this question of total number of quotes = 0.4%

% articles which referred to this question of total number of articles = 2.3%

Response of neonatologists	No. of quotes
No other factors should influence the decision	1
No legal problems exist, if everything is documented	1
Would pursue poor prognosis child if family desired	1

Table 6: In making the decision of whether or not to treat, whose interests are the most important: the neonate's, the family's, or society's?

Response in the literature	No. of quotes	% of total no. of quotes	No. of articles
The best interests of the infant are far superior	22	68.8	14
In an overview, must also consider massive costs to society	10	31.2	5

% quotes which referred to this question of total number of quotes = 11.2%

% articles which referred to this question of total number of articles = 43.2%

Response of neonatologists	No. of quotes	% of total no. of quotes
The best interests of the infant are far superior	5	71.4
Society, unfortunately, has some effect	2	28.6

RESULTS AND DISCUSSION

Responses to question one--"How would you define a severely defective newborn?"--are summarized in Table 1. The significant point about the way this question is dealt with in the literature is that there is little discussion of what constitutes a severely defective newborn and even less agreement about it. The definitions vary widely, and few writers are specific about the conditions they consider "severe". Many stress that nearly all babies are treated, and that only the most serious cases are considered for non-treatment, but no conclusion is ever reached about how, specifically, a defective newborn is defined.

The neonatologists in the interviews were less ambiguous than the literature. Two of the three doctors emphasized the importance of severe limitations in function, while one simply defined a severely defective newborn as one with severe congenital anomalies. It is interesting that function is rarely mentioned in the literature; debate usually centers around morphological syndromes and conditions, which of course affect function. It was pointed out both in the literature and in the interviews that the definition of severely deformed changes not only with time and the development of new technology, but also with location and the availability of sophisticated technology.

Responses to question two--"Do you make an all-out effort to save the life of every live-born infant, even

those that fit your definition of severely defective?"--are summarized in Table 2. About twice as many statements (68.7%) were in favor of refraining from treatment in certain cases as advocated maximal treatment in every case (31.3%). Twenty-nine out of fourty-four, however, did not specify the conditions in which they would withhold treatment. Of those that did specify reasons for non-treatment, 2.4 times more statements indicated that their writers would make decisions based on the projected quality of life of the infant than would judge solely on whether or not the baby was expected to live, even with treatment. It is important to note that "ordinary means", such as warmth and nourishment, are never in question; the controversy lies in the decisions about "extraordinary means". Furthermore, definitions of "ordinary" and "extraordinary" are not generally given, and obviously are dependent upon the availability of treatment facilities.

The neonatologists who were interviewed showed a much stronger tendency toward going all-out to save every infant's life than was seen in the literature analysis. Two of the three said that they refrained from treatment only if it was apparent that the baby would die, even with treatment; only one mentioned the quality of life the child might have if it survived. The trend toward making the all-out effort seems to increase with the degree of specialization and the level of technology of the hospitals with which the doctors are associated, but the number of interviews was not great enough to make a definitive statement.

Responses to question three--"Who do you feel should be involved in the process of deciding whether or not to treat an infant, when there is time to make the decision?"--are summarized in Table 3. The position that parents should, in most cases, have the final say about treatment or non-treatment of their infants is by far the most common stance taken in the literature, with 49.3% of the quotations which address the question favoring this viewpoint. Most proponents, however, do point out that some instances may arise where the doctor can not agree with the parents' decision. In such cases, some advocate the intervention of courts of law in making the final decision.

Of those who do not feel that the parents should be the primary decision-makers, 2.3 times as many argue that the power of treatment decisions should be left in the hands of the medical staff of the hospital as contend that a neutral third party should decide. On the other hand, 1.6 times as many statements are made by those who argue that doctors should not be responsible for decisions as are made by those who hold that a third party should not intervene.

Two main reasons are put forth for not involving parents in the decisions. Some say that the family is undergoing severe emotional strain and cannot comprehend the medical diagnosis or the ensuing consequences of their decision, and should not be asked to attempt it. Others maintain that the parents, rather than representing the

best interests of the infant, have a conflict of interests with their own needs and desires and are therefore biased in their decision making.

The need for education of and effective communication between parents and doctors is at times mentioned. Another concern is that maximum care should be provided at first, and treatment decisions should be made when all involved parties are rational and can have time to consider their decision.

Two of the neonatologists placed very strong emphasis on the primary role of the parents in decision making. They did, however, like the literature, point out that doctors must at times disagree with parents' decisions. The third doctor seemed to feel that the decision was primarily a medical one, and that the medical staff was the most appropriate decision-maker, although the parents should have some input into the decision. Two of the doctors emphasized the importance of giving the parents clear and full information and explanations of the situation. Two of them also mentioned the difficulty of very early diagnosis and prognosis, and indicated that they preferred to treat the baby at first, then make decisions at a later time after careful consideration of all available information.

Responses to question four--"What criteria do you use to decide whether an infant should be treated?"--are summarized in Table 4. Like the definition of severely defective, this question is infrequently addressed in the liter-

ature (8.7% of total quotations). Again, it is the lack of agreement among writers which is significant, not the particular criteria which are advocated by specific authors. No single criterion or set of criteria is mentioned often enough to have any particular import.

The neonatologists, like the literature, were not very specific in their answers. They all agreed that they would, at least initially, provide treatment unless the baby's condition was incompatible with life. Much emphasis, however, was placed on the individuality of cases and the impossibility of developing rigid criteria for treatment decisions.

Responses to question five--"What factors other than the physical condition of the infant may influence your decision?"--are summarized in Table 5. Many nonmedical factors which may have a bearing on treatment decisions are mentioned in the literature. The most frequently discussed is the effect on the family of treating and attempting to rear a severely defective child. Two-thirds of the statements of writers who discuss the controversy indicate that these effects are at least considered, while one-third of the quotations are by those who do not feel that the family's concerns are legitimate considerations when deciding about the life of the neonate.

Other factors are also discussed. The ambiguous legal situation is often mentioned, but it is not debated hotly. The projected quality of life of the child, as a criterion

for treatment, is on the other hand a subject of much disagreement.

None of the neonatologists commented very much about this question. The question may not have been worded clearly enough to obtain a good answer. Alternatively, it may be that the doctors prefer to consider these situations primarily medical ones, or at least ethical ones based on medical facts and conditions, and do not feel that other factors are or should be relevant.

Responses to question six--"In making the decision of whether or not to treat, whose interests are the most important: the neonate's, the family's, or society's? If you see a strong conflict among these, whose interest should take precedence?"--are summarized in Table 6. The "best interests of the infant" is a common theme through much of the literature. The problem lies in the fact that few writers agree on what the best interests of the infant are, particularly whether or not life can be contrary to the child's best interests. The great financial cost to society of treatment is mentioned by some, but these writers would still, on an individual basis, put the baby's best interests first. None of the wrtiers put the interests of the family before those of the child, although proponents of consideration of family problems might argue that what is against the family's interests is not good for the child.

All of the doctors agreed that the infant was the most important party to consider. Two mentioned the negative effects of society's "interests", such as the shortage of funds and the pressures to behave in certain given ways. One of the doctors mentioned quality of life as a consideration in determining what is best for the neonate; the others appeared to assume that life is in the child's best interests, if that life can be prolonged, or "saved".

CONCLUSIONS

There is little agreement about the conditions which define a defective newborn. The majority of writers feel that in some cases an all-out effort to save an infant's life is not appropriate. Neonatologists, as interviewed, seem to agree, but tend to limit non-treatment primarily to those babies who would die even with treatment. Most writers and doctors feel that the parents should be the primary decision makers, although others favor decision-making by the medical staff or by a neutral third party. Criteria for treatment or non-treatment of severely deformed newborns vary as much as do definitions of severely defective infants. The influence of many nonmedical factors was discussed in the literature, but neonatologists did not mention many such factors. In both the literature and in interviews with neonatologists, the best interests of the infant are given primary consideration.

RECOMMENDATIONS

The first step to be taken in attempting to deal with the difficult problems of making treatment decisions about defective newborns is to develop a widely accepted definition of what "severely defective" is. No valid ethical decisions can be made until the foundations are laid by defining the terms used in the discussion of the topic. Complex and tortuous as any such definition would be, it is still a prerequisite for any serious consideration of the controversies surrounding decisions about treatment of defective newborns.

Further study of attitudes among neonatologists concerning treatment decisions is needed. A nationwide survey might be an effective means of discovering these attitudes. Categorization of responses by the size and degrees of technology and specialization of the hospitals with which the respondents are associated would be helpful.

Both the medical and the lay communities need to become more aware of the ethical issues which surround decisions about defective infants. Only through discussion and serious self-examination can we hope to reach decisions based on rational thought rather than on uncontrolled emotion. We must live with the decisions we make; we should try to ensure that our decisions will be thoughtful, caring, and legitimate ones.

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APPENDIX

1. Initial letter to neonatologists
2. Reply postcard with informed consent statement
3. Report sheets used in interviews

BALL STATE UNIVERSITY MUNCIE, INDIANA 47306

The Honors College

Phone: (317) 285-1650

Botsford Hall, Box 32
Muncie, IN 47306
23 April 1982

Dear Dr.

As you are doubtless aware, there has been much interest lately in the ethics of decision-making in neonatology. I am a senior at Ball State University, and will be attending the State University of New York Upstate Medical Center College of Medicine next fall on an Air Force Health Professions Scholarship. For my Senior Honors Thesis (a part of the curriculum of the Honors College at Ball State), I am working on a research project to determine current attitudes among neonatologists concerning certain ethical issues dealing with severely deformed newborns. I have been awarded an Undergraduate Research Grant by Ball State University to help cover the costs of travel and a computer search; a copy of the grant proposal, explaining the project, is enclosed. My thesis advisor, Dr. Jon Hendrix, is the director of the Human Genetics and Bioethics Education Laboratory at Ball State.

The main purpose of my research, as I explain in the enclosed proposal, is to discover prevalent attitudes in the current literature and to assess the validity of these attitudes through personal interviews with neonatologists. Thus, you can see that your participation in the project would be of great assistance to me. If you would be willing to help me in the collection of my data, I would like to conduct an interview with you. This interview would take no more than one half hour of your time. It would consist of a series of questions regarding your attitudes. You would, of course, be free to decline to answer any question or questions or to terminate the interview at any point. All information collected will go immediately into a data pool; there will be no records kept which could connect you with your responses. Complete anonymity will be ensured. If you would be willing to participate in this study, please contact me by returning the enclosed post card so that I may call to arrange an interview appointment at your convenience.

Please feel free to contact me if you have any questions regarding the interview or the research in general. My home telephone number is (317) 285-5150; I can usually be reached there after 6:00 p.m., or I can return your call if a message is left during the day. Thank you for your consideration,

Sincerely,

Mary L. Dizer
Principal Investigator

☐ I am willing to be interviewed by Mary Dizer concerning my attitudes on certain ethical issues in neonatology. I understand that I may refuse to answer any question or questions, that I may end the interview at any time, that I am assured complete anonymity, and that the interview will take no more than a half hour. Please list the phone number through which an interview appointment may be arranged:

_____

☐ I prefer not to consent to such an interview.

Signature: _____

Date: _____

1. How would you define a severely defective newborn?

2. Do you make an all-out effort to save the life of every live-born infant, even those that fit your definition of severely defective?

3. Who do you feel should be involved in the process of deciding whether or not to treat an infant, when there is time to make the decision?

4. What criteria do you use to decide whether an infant should be treated?

5. What factors other than the physical condition of the infant may influence your decision?

6. In making the decision of whether or not to treat, whose interests are the most important: the neonate's, the family's, or society's? If you see a strong conflict among these, whose interest should take precedence?